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GRANT NUMBER DAMD17-96-1-6191

TITLE: Delays and Refusals in Treatment for Breast Cancer Among
Native American and Hispanic Women with Breast Cancer

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REPORT DATE: August 1997

TYPE OF REPORT: Annual

PREPARED FOR: Commander
U.S. Army Medical Research and Materiel Command
Fort Detrick, Frederick, Maryland 21702-5012

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DTIC QUALITY INSPECTED 2

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503.

1. AGENCY USE ONLY (Leave blank)		2. REPORT DATE August 1997	3. REPORT TYPE AND DATES COVERED Annual (1 Aug 96 - 31 Jul 97)	
4. TITLE AND SUBTITLE Delays and Refusals in Treatment for Breast Cancer Among Native American and Hispanic Women with Breast Cancer			5. FUNDING NUMBERS DAMD17-96-1-6191	
6. AUTHOR(S) Dr. Elba L. Saavedra Dr. Elias Duryea				
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) University of New Mexico Albuquerque, New Mexico 87131-5141			8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING/MONITORING AGENCY NAME(S) AND ADDRESS(ES) Commander U.S. Army Medical Research and Materiel Command Fort Detrick, Frederick, Maryland 21702-5012			10. SPONSORING/MONITORING AGENCY REPORT NUMBER	
11. SUPPLEMENTARY NOTES				
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for public release; distribution unlimited			12b. DISTRIBUTION CODE	
13. ABSTRACT (Maximum 200) <p>Purpose: The purpose of this study is to identify and describe the factors associated with delays in breast cancer treatment as mediated by psycho-social, cultural, and demographic variables among Hispanic, Native American and non-Hispanic white women.</p> <p>Scope: The study will enroll a total of 70 participants, 35 patients and 35 family members or other caregivers identified by the patient. This ethnographic study will gather qualitative data through the use of an interview guide and a semi-structured interview. Interviews will be conducted for a minimum of two sessions. The location of the interviews will be chosen by the patient or caregiver. The study will seek input and assistance from community individuals and organizations such as tribal Community Health Representatives (CHRs), the Native American cancer support group "The Gathering of Cancer Support", People Living Through Cancer, and the American Cancer Society.</p> <p>Summary: A strong foundation for the implementation of the study of has been laid in this formative stage. Study methods have been clarified, the population has been identified, and the instrument is largely designed. Perhaps most significantly, a strong network of professional and community contacts has been developed, without which the smooth implementation of the study would be impossible.</p>				
14. SUBJECT TERMS Breast Cancer			15. NUMBER OF PAGES 60	
			16. PRICE CODE	
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited	

FOREWORD

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Elba L. Llanedra 10-22-97
PI - Signature Date

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5. Introduction (Background Information)

New Mexico Demographics

New Mexico's economic status, ethnic diversity, and rural character present special challenges to cancer control efforts in our state. Barriers to breast cancer care that have been documented elsewhere in the nation are exacerbated by these characteristics of the state.

Poverty

New Mexico ranks 47th in the country in per-capita income, with an income level 22% lower than the national average. The percentage of persons living below the poverty level is 25.3% statewide. Forty-six percent of Native Americans and 28% of Hispanics live below the national poverty level. The counties with the highest percentage of families below the poverty level are McKinley, Guadalupe, Mora, Cibola, and San Miguel. All have a high proportion of Hispanics and/or Native Americans¹.

Ethnicity

New Mexico is one of the most culturally diverse states in the country. The population is divided into four main ethnic groups: 50.4% non-Hispanic white, 37.5% Hispanic, 8.9% Native American, and 2% African-American. These groups are in turn made up of diverse subgroups¹.

Native Americans in New Mexico represent three major groups: the Navajo, Pueblo, and Apache (Jicarilla and Mescalero). The Pueblo tribes include 19 independent communities with different customs and languages. Hispanics can be divided into two major groups: the descendants of Spanish colonization centered in the Northern part of the state, and recent

immigrants from Mexico, a large number of whom reside in the southern part of the state².

Rural Character

New Mexico is predominantly rural, with an average population density of only 13.3 persons per square mile¹. According to the 1990 census, six of New Mexico's thirty-three counties were considered 100% rural. Only four counties in New Mexico are classified as urban (more than 75% of the population is urban).

Breast Cancer Epidemiology

The American Cancer Society (ACS) estimates that in 1997, 180,200 new breast cancer cases will be diagnosed among women in the United States³. This year, 43,900 women are expected to die from breast cancer. One out of every eight women will eventually develop breast cancer by age 85.

National data reveal that breast cancer incidence varies significantly among racial and ethnic groups in the United States^{4,5}. In comparison with non-Hispanic whites, lower incidence rates have been reported for African-Americans, Asians, Native Americans, and Hispanics⁴.

Incidence in New Mexico

In New Mexico, the ACS estimates that in 1997, 970 cases of breast cancer will be diagnosed and approximately 240 women will die of the disease⁶. Only lung cancer causes more cancer deaths among women in New Mexico. Breast cancer incidence and mortality rates are higher for non-Hispanic white women than for women of other ethnic groups in the state, but are comparable with those for non-Hispanic white women nationwide.

The pattern of breast cancer incidence varies widely among New Mexico's three main racial and ethnic groups: non-Hispanic whites, Hispanics, and Native Americans. New Mexico Tumor Registry (NMTR) data from 1969-1995 show an increasing incidence of breast cancer for all groups. The incidence of breast cancer for Hispanic and Native American women, though considerably lower than that of non-Hispanic white women, has doubled in this 25 year time period⁷.

Since 1988, the age-adjusted incidence rates of breast cancer among non-Hispanic white and Hispanic women have remained relatively unchanged. Native American women show a large increase in the same time period, from 32 to 42 cases per 100,000⁷. Much of this increased incidence is attributable to increased detection through the initiation of mobile mammography services in rural areas of the state.

Stage of Disease at Diagnosis

Diagnosis of breast cancer at an early stage is strongly linked to improved prognosis. The stage at diagnosis of breast cancer for all women in New Mexico has improved substantially in the past decade. Data from the periods 1986-1990 and 1991-1995 show that the percentage of local stage disease (no spread to other areas) among non-Hispanic white women has increased from 53.2% to 56.4%. The percentage of in-situ disease (the earliest type) among non-Hispanic white women increased from 11.0% to 14.7%⁷.

Historically, Hispanic and Native American women have presented with more advanced (later stage) disease at the time of diagnosis when compared to non-Hispanic white women. Local stage breast cancer increased for Hispanic women during this time period from 46.0% to 51.3%. In-situ disease increased from 8.8% to 12.7%. Native American women showed the greatest increases of early stage disease. Local stage disease went up from 40.6% to 50.4% and in-situ from 6.3% to 11.9%⁷.

Mortality

The average annual age-adjusted mortality rate for breast cancer in New Mexico, for the time period 1993-1995, for non-Hispanic white women was 25.6 per 100,000. For Hispanic women, the rate was 17.7 per 100,000, and for Native American women, the rate was 8.0 per 100,000⁷.

Survival

The 5-year survival rate among New Mexico women with breast cancer between 1973-1995 was 79% for all stages, 89% for local disease, 69% for regional disease, and 21% for distant stage disease⁷. Fewer Native American and Hispanic women are diagnosed with breast cancer than non-Hispanic whites, but those that do get the disease are less likely to survive. Survival rates for Native American women are 69% and Hispanic women 72%, compared to 83% for non-Hispanic white women⁸. Data from the NMTR suggest that part of this difference is due to later stage and larger tumor size at the time of diagnosis, though other variables such as tumor growth rate and genetic susceptibility are currently under study.

Issues in Breast Cancer Care

Breast Cancer and Ethnicity

Few studies have examined the experiences of breast cancer treatment among various ethnic groups. In particular, barriers to treatment and noncompletion of breast cancer treatment have not been extensively studied among Native American and Hispanic women. Current breast cancer research focusing on these populations in New Mexico has been primarily epidemiological in nature^{8,9}. There is one current multi-site study, which includes New Mexico data, examining the knowledge, attitudes, beliefs, and acculturation level of Hispanic breast cancer patients in relation to treatment compliance. Similar to the investigator's study, this study attempts to delineate the potential barriers to compliance with treatment among a specific ethnic group, Hispanic women. It differs in its use of quantitative rather than qualitative methods.

Qualitative Methods

Qualitative methods (in-depth interviews) have been used to examine the experiences of women treated for breast cancer^{10,11,12,13}. Few of these studies have examined women from a specific ethnic or racial group who have experienced delays in breast cancer care. Matthews, Lanin, and Mitchell (1994) reported the results of in-depth interviews with 26 older, less educated, rural African-American women diagnosed with advanced breast cancer. These women were found to have delayed a significant length of time before seeking care for their symptoms.

Financial Barriers

The body of research examining breast cancer treatment among low income women and women of diverse backgrounds suggests the need for further research to evaluate the reasons for the disparities in treatment and survival

among underserved women^{15,16,17}. The difficulties experienced by cancer patients in obtaining and maintaining their health insurance after diagnosis presents an added burden to the patient^{18,19}.

Treatment Decisions

Debra Long (1993) reviewed the literature on the determining factors that guide a woman's choice of treatment, and suggests that women need to be better educated about their treatment options. It is suggested that men in the patient's family also be included in educational activities. Siminoff and Fetting (1991) also reported on the significance of physicians providing adequate information to their patients. The findings of this study indicate that patients want more specific information on treatment and disease, to assist them with their choices and their discussion with their physicians.

Cultural Practices

Improved provider understanding of the cultural influences on patients' treatment decisions, including traditional health practices, also has been cited in the literature as necessary to optimize the benefits of the patient-provider partnership^{22,23,24}. Providers need to consider cultural influences on the response to pain, comfort issues, and the role of spirituality, that exist among ethnic groups. By familiarizing themselves with the cultural practices of the given ethnic group, providers may be more successful in meeting the patients' needs related to treatment^{25,26}.

Quality of Life

Topics related to survivorship and the quality-of-life of breast cancer patients also need further investigation. In particular, more focus on the breast cancer patient's family, especially the coping mechanisms and support needed by children of cancer patients, is needed^{19,27}.

Previous Work

The investigator's earlier work analyzed the time intervals between abnormal finding and treatment of breast cancer among Native American, Hispanic, and non-Hispanic white women. This original research showed several trends among these populations in the evaluation and treatment of breast cancer in New Mexico. The findings confirmed a continued trend toward early diagnosis for all women, especially Native American women. In this study, a large majority (83 percent) of the women enrolled in the B&CC Program underwent diagnostic evaluation within the program's suggested guidelines for timeliness. While the results for most of women in this study were very encouraging, the existence of a subset of women who experienced delays in diagnosis (17 percent) or treatment (15 percent) requires further examination. Further research is needed to define the patient, provider, and facility characteristics which explain these delays and any impact they may have on survival²⁸.

Subject

A substantial body of literature supports the critical importance of early diagnosis and treatment for improving prognosis in breast cancer. Despite the widely acknowledged importance of timeliness in diagnosis and treatment, little is known about delays occurring during treatment. Nearly all of the existing literature focuses on the screening and diagnostic phases of breast cancer care. If delays exist during treatment, the benefits of early detection achieved through widespread mammography screening could be lost. Previous studies have documented the progression of disease during delays in diagnosis and treatment^{29,30}. Characterization of those delays will identify explanatory factors and suggest interventions to improve outcomes.

Purpose

The purpose of this study is to identify and describe the factors associated with delays in breast cancer treatment as mediated by psycho-social, cultural, and demographic variables among Native American (Pueblo and Navajo), Hispanic (including subgroups in the state) and non-Hispanic white women. An ethnographic qualitative design will utilize comprehensive in-depth interviews to achieve this goal.

Scope of the Research

The study will enroll a total of 70 participants, 35 patients and 35 family members or other caregivers identified by the patient. Qualitative data will be gathered through the use of an interview guide and a semi-structured interview. Interviews will be conducted for a minimum of two sessions, as needed for completion of data collection. The location of the interviews will be chosen by the patient or caregiver. The study will seek input and assistance from community individuals and organizations such as tribal Community Health Representatives (CHRs), the Native American cancer support group "The Gathering of Cancer Support", People Living Through Cancer, and the American Cancer Society.

6. Body (Design and Methods)

The following section will address Tasks 1, 2, 4 and 5 from the Statement of Work Year 01 submitted with the original proposal.

Conceptual Framework of Delays in Breast Cancer Care

In the course of the past year, an expanded and more clearly defined conceptual framework has been developed for the factors influencing delays in breast cancer care (Appendix A). The patient's experience with the clinical diagnostic evaluation and treatment can be impacted by three broad classes of mediating variables, those related to the patient, the provider, and the health care system. These variables influence the type of resolution (completion or non-completion of treatment) which ultimately impacts outcomes. The relative impact of each of these variables is filtered through the cultural perspective through which a woman views her life experiences.

Design

As discussed in the original proposal, the design of this study will use a ethnographic approach comprised of in-depth interviews. Perceptions of an illness such as breast cancer are influenced, in part, by the characteristic ways in which medical conditions and corresponding situations are framed and interpreted. The ethnographic approach allows us to understand actions in the context the shared framework of meanings that constitutes "culture"³¹.

An important goal of the first year of this study has been to gain a better understanding of the varied cultures of the women involved in this study. To accomplish this goal, contacts have been made with a wide variety of persons and organizations representing differing aspects of those cultures.

Consultants to the Study

In this formative phase of the study, the investigator has sought out and met with breast cancer survivors', representatives of state and tribal agencies, clinicians, and advocacy organizations, to elicit feedback on the study's design, the interview guide, identification of participants, and tribal approval of the study. These informal (one on one meetings) and formal (mailed response requested) contacts have been tremendously helpful for validation of the design, development of study protocols, gaining insight into the study population, expanding knowledge of the disease, and most importantly for enhancing community partnerships. These ground level efforts will prove instrumental to ensuring the quality of the data collected and the acceptance of the study by the study participants and agencies involved.

One example of the significance of this informal data gathering is the series of meetings held with Ms. Mary Lovato, the director of the Gathering of Cancer Support in New Mexico. Ms. Lovato is a member of the Santo Domingo Pueblo. She was asked to suggest helpful ways to increase the participation of Pueblo women who will be identified in the study. Ms. Lovato suggested the use of the support groups sponsored by the Gathering of Cancer Support at the Pueblos as a way to "break the ice" and build trust prior to scheduling individual interviews with the women. She also enthusiastically offered her services for interviewing, as well as the assistance of another cancer survivor from the Pueblo. These discussions have proved helpful for outlining a culturally appropriate approach to data gathering with the Pueblo women.

Another important contact is Ms. Martina Callaghan, a community health nursing consultant for the Indian Health Service (IHS). Her collaboration has provided a list of Pueblo community women who will be of assistance because they speak the languages, know the culture, and/or have themselves had cancer. Ms. Callaghan, who is part Hispanic and Hopi, is an experienced

administrator familiar with the field experiences of the IHS public health nurses and the communities they serve. Similar discussions with these and other community representatives will continue, in order to facilitate the implementation of the study in these communities.

Identification of Study Participants

The study population will include Native American, Hispanic, and Non-Hispanic white women diagnosed with breast cancer and their families, as was stated in the original research proposal. Over the past year project collaborations with the Breast and Cervical Cancer (B&CC) Program and the New Mexico Tumor Registry have increased substantially. The investigator has met with Dr. Charles Key of the New Mexico Tumor Registry (NMTR) and Anita Salas of the New Mexico Breast and Cervical Cancer Detection and Control (B&CC) Program, and has finalized the protocol for identification of study participants. Pending approval from the University of New Mexico Health Sciences Center Human Research Review Committee (HRRC), the NMTR and the B&CC program will make available a matched breast cancer data file for the selection of cases.

The investigator, with input from the B&CC Program and the NMTR, has developed an abstract form to be used while reviewing case records to identify cases at both the B&CC Program and NMTR (Appendix C). The investigator is experienced in medical abstracting and is familiar with this database from previous work, and will conduct the reviews. The study will utilize a criterion sampling technique, consisting of all cases that meet the criteria of the study, cases where treatment has been delayed or refused. A delay or refusal is defined as any documented variation from the recommended plan of treatment resulting from the patient's actions or decisions. Records will be reviewed back to 1991, the time at which the B&CC Program began operations. Once the abstracting of the records is completed, the investigator

will make arrangements to abstract further records from the physicians and clinics of identified cases, to ascertain the follow-up protocols that were followed with each patient.

Increased familiarity with the NMTR database has heightened the investigator's understanding of both its capabilities and limitations. While the NMTR registry abstractors collect data on treatment modalities, dates of treatment, and other pertinent clinical information, they often do not have records of the reasons for missed appointments or refusal of recommended treatment. The NMTR does maintain records of the identity of the physicians and hospitals, and the patient status and follow-up. This information is very important to the study for a number of reasons. It allows the investigator to plan from what sources additional patient data will be obtained and investigate the procedures required by those physicians or hospitals to obtain access to those records. These procedures will then be included in the requests for human subject research approval to the University of New Mexico and IHS institutional review boards.

Interview Guide

As outlined in the original proposal, the study will use a semi-structured interview approach. These in-depth interviews will be conducted in a manner that permits a wide range of information to be elicited on the psychosocial, cultural, and attitudinal variables associated with delays and refusals of treatment of breast cancer among Native American, Hispanic, and non-Hispanic white women. The interviews will also elicit family member's perceptions of breast cancer, their knowledge and understanding of breast cancer treatment, the impact of treatment decisions on the family, and how they see themselves providing support or assistance.

The investigator has reviewed questionnaires published in the literature examining similar variables among patients with breast cancer (Appendix D). The topic areas derived from this literature and from the investigators personal experience were then cross checked by experts in the field and study consultants. From the revised topic areas, two draft sets of questions are being drawn up for the study participant and caregivers. Feedback from consultants continues to be received. The draft questions will then be reviewed by faculty mentors and specialists in qualitative research methods. After further revision, these questions will be pretested to form the basis of the interview guide. This developmental process is expected to be completed by December 1997 (Appendix E).

Planned Analysis

Qualitative coding and narrative analysis will be conducted using Hyper Research, a qualitative analysis software program that aids the researcher in handling, coding, and analyzing large quantities of data. Thematic coding will be used to examine all verbatim transcribed interviews for psychosocial, cultural, attitudinal, and other variables associated with the management and coping of breast cancer, particularly treatment effects and variables associated with treatment delay, refusal, or completion. Narrative analysis will be used to examine meanings of breast cancer illness and disease. The investigator is also currently studying the comparative strengths of the QSR NUD-IST software relative to Hyper Research (Appendix G).

Recent Developments

Navajo Breast and Cervical Cancer Project

As of October 1996 the Navajo Nation Division of Health was funded through the Centers for Disease Control to provide cancer screening services to Navajo women. The New Mexico Breast and Cervical Cancer Program has worked closely with the newly formed Navajo Breast and Cervical Cancer Project to exchange information, assist in the development of their infrastructure and to facilitate the provision of services. The organizational structure of Navajo Division of Health has continued to evolve with their new responsibilities. In late summer of 1997, the Navajo Breast and Cervical Cancer Project was transferred into the research component of the Navajo Division of Health. The investigator has been in contact with the health research liaison representative of the Navajo Nation and has arranged meetings to discuss the present study. These contacts will be ongoing and are crucial to building a working partnership with the Navajo Nation Breast and Cervical Cancer Project.

Navajo Nation Health Research Review Board

Significant recent developments have also occurred between the Navajo Nation and the Navajo Area Indian Health Service, regarding the transition of the functions of the IHS institutional review board to the Navajo Nation. In January 1996, the Navajo Nation Research Code became law, creating the Navajo Nation Health Research Review Board (NNHRRB) to assume the previous functions of the Navajo Area Research and Publication Committee of the IHS. As a result, the NNHRRB is now the institutional review board for the Navajo Nation. On March 14, 1996, the Navajo Division of Health research program assumed responsibility for the administrative processing of research proposals and manuscript review. The investigator is awaiting

further information concerning submission of the study to the NNHRRB under protocols which at this date are still being revised.

Future meetings are currently being planned with the liaison from the Navajo Nation research program, the Indian Health Service, and the New Mexico B&CC Program to discuss the collaborations surrounding this current study. Dr. Nathaniel Cobb, director of the Albuquerque Area IHS Cancer Prevention and Control Program, noted the significance of this study for the Navajo Breast and Cervical Cancer Project, as a source of feedback for development of the program's case management and follow-up protocols.

Institutional Review Processes

The proposed study has developed protocols for recruitment of the research participants. No changes have been made that will pose potential risks to research participants. There are no physical risks to participants in any aspect of the various research projects. Attention has been given to benefiting all participants with educational materials and/or financial reimbursement.

The status of the IRB submissions for the study at the various institutions is as follows:

- University of New Mexico Main Campus Human Research Review Committee: Submitted and approved on February 18, 1996.
- University of New Mexico Health Sciences Center Human Research Review Committee. To be submitted by mid November.
- National Indian Health Services (IHS): As a result of Navajo Nation newly created IRB, new guidelines will be forwarded from Dr. Nathaniel Cobb from the Albuquerque Area Headquarters West - Cancer Control and Prevention Division. To be submitted in mid November.

- Navajo Area Indian Health Service (IHS): Now handled by the Navajo Nation Health Research Review Board. New guidelines continue to be reviewed by the Navajo Nation. Currently in the process of holding meetings with the research liaison to review requirements. Submission planned by mid November.
- Presentations by the investigator will also be made to the All Indian Pueblo Council and Pueblo Governors.

Summary

In summary, a strong foundation for the implementation of the study of has been laid in this formative stage. Study methods have been clarified, the population has been identified, and the instrument is largely designed. Perhaps most significantly, a strong network of professional and community contacts has been developed, without which the smooth implementation of the study would be impossible.

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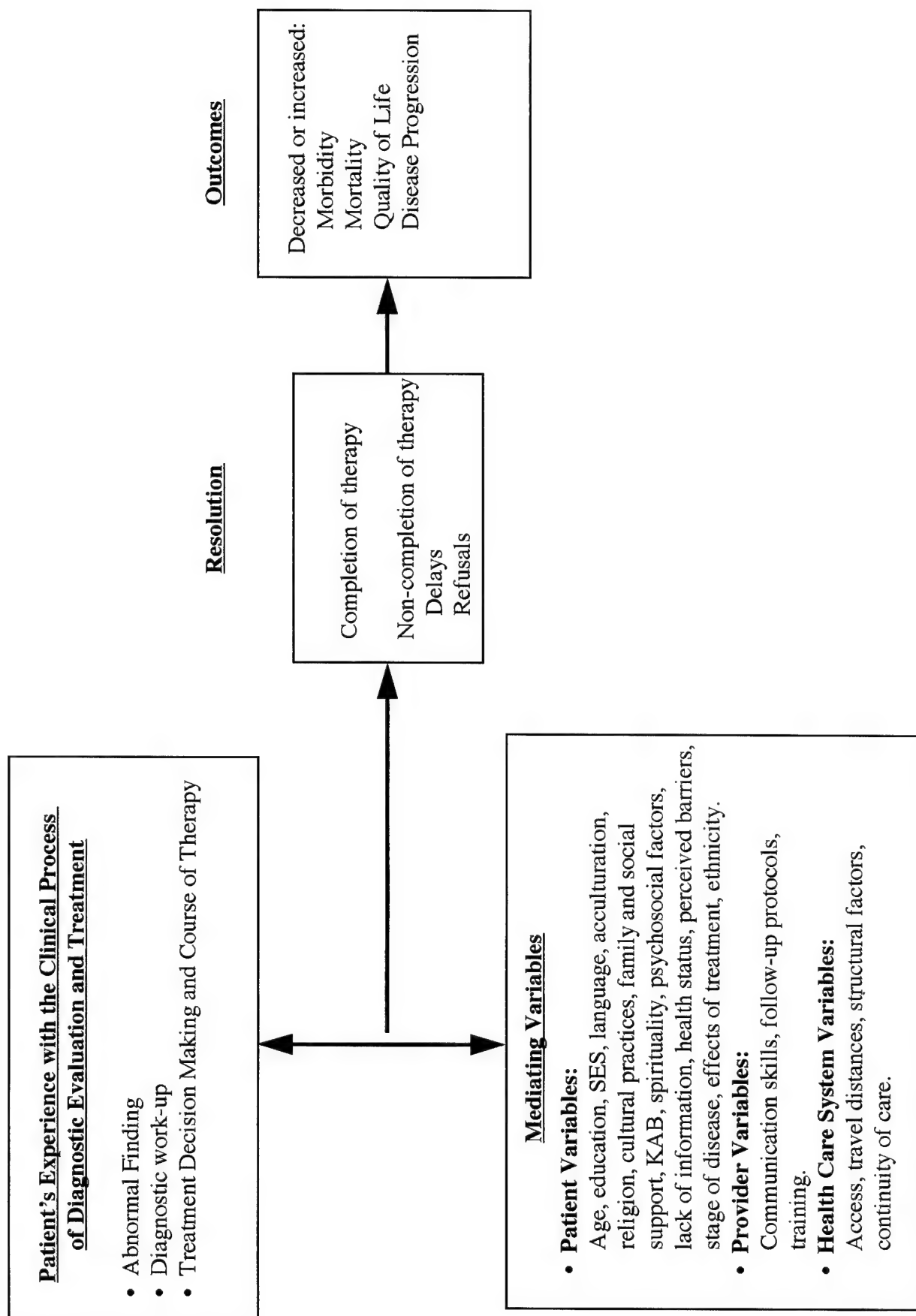
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APPENCIES

APPENDIX A

**CONCEPTUAL FRAMEWORK OF
DELAYS IN BREAST CANCER CARE**

Conceptual Framework of Delays in Breast Cancer Care



APPENDIX B

LIST OF CONSULTANTS TO STUDY

List of Consultants

Anita Salas, MA
Program Manager

New Mexico Breast and Cervical Cancer Program

* Ms. Salas is responsible for overseeing the B&CC Program and assists in the identification of the study participants through its breast cancer database. Ms. Salas provides her expertise on programmatic matters related to the breast cancer database.

Louise Lamphere, Professor of Anthropology
Department of Anthropology
University of New Mexico

*Dr. Lamphere provides the anthropological perspective on Hispanic and Native American communities in New Mexico.

Sylvia Ramos, MD Private Practice
Clinical Associate Professor of Surgery
University of New Mexico Health Sciences Center

*Dr. Ramos is an experienced breast cancer surgeon, and is familiar with the clinical aspects of breast cancer treatment. Ms. Ramos is Hispanic, and is bilingual and bicultural.

Nathaniel Cobb, MD, Director
Carol Johnson, MPH - IHS- Cancer Prevention and Control.
Ben Muneta, MD - IHS- Cancer Prevention and Control.
Indian Health Service (IHS) Cancer Prevention and Control Program
Albuquerque, New Mexico.

*Dr. Cobb and his staff provide knowledge of tribal regulations and institutional review board (IRB) approval process of the various Native American tribes and the cancer control efforts among Native Americans in the state.

Dr. Alan Waxman, Senior Clinician Obstetrics and Gynecology
Indian Health Service OB/GYN Practice
Gallup, New Mexico.

*Dr. Waxman provides knowledge of the clinical aspects of the disease and is familiar with mammography screening among Native American women.

Mary Lovato, Director
Gathering of Cancer Support
Santo Domingo Pueblo, New Mexico.

*Ms. Lovato is a cancer survivor, an experienced support group leader and is familiar with Pueblo culture. Ms. Lovato is from the Santo Domingo Pueblo.

Dr. Charles Key, MD, Ph.D.
Professor, Medical Director
University of New Mexico Tumor Registry
Cancer Research and Treatment Center

*Dr. Key is an experienced cancer epidemiologist and director of the NMTR.
Dr. Key is also familiar with the B&CC Program database and with New Mexico's ethnic populations.

Margaret Whalawitsa, BA
Health Promotion Specialist
Women's Health Project
Northern Navajo Medical Center
Shiprock, New Mexico

*Ms. Whalawitsa is experienced in conducting focus groups with Navajo women in breast and cervical cancer screening. Ms. Whalawitsa is a member of the Navajo Nation.

Sylvia Sepien
Project Director
La Clinica De Familia Promotora Project

*Ms. Sepien is an experienced community health worker, especially familiar with the experiences of Hispanic women. Ms. Sepien is bilingual and bicultural.

Regina Martinez
Reach to Recovery
American Cancer Society (ACS)

*Ms. Martinez is an experienced volunteer with the ACS working with assisting Hispanic breast cancer patients and their families. Ms. Martinez is bilingual and bicultural.

Melvina McCabe, MD
Assistant Professor
Family and Community Medicine Department
University of New Mexico

* Dr. McCabe's area of specialty is in gerontology and in health related issues among the Navajo Nation. Dr. McCabe is a member of the Navajo Nation.

Carmelita Davis
Program Manager
Navajo Breast and Cervical Cancer Project
Window Rock, Arizona

*Ms. Davis is program director to the newly formed B&CC Project at Navajo.

Ms. Davis will participate as a collaborator and advise on issues related to program enrolled Navajo women and mammography screening.

Carolyn J. Wood, Ph.D.

Professor

Educational Administration

College of Education

University of New Mexico

*Dr. Wood is an experienced qualitative researcher in the field of education.

Ms. Wood is currently teaching qualitative methodology at the College of Education.

William Freeman, MD, MPH

Director of Medical Systems Research and Development

Albuquerque Area Indian Health Services

*Dr. Freeman is knowledgeable in qualitative methodology and IRB guidelines at IHS and the Navajo Nation. Dr. Freeman is an experienced researcher and familiar with research among the Navajo Nation and the Pueblos.

APPENDIX C

**MEDICAL ABSTRACT FORM AND
CODE SHEETS**

PATIENT DIAGNOSTIC AND TREATMENT SUMMARY REPORT

PART I. DEMOGRAPHICS

STUDY ID #: _____ Ethnicity: _____
(If Code 05, specify: _____)
Clinic #: _____ Town: _____ Zip Code: _____

PART II. BREAST AND CERVICAL CANCER PROGRAM DATA

A. Screening Cycle With Diagnosis Of Breast Cancer.

Test with abnormal result (choose one):

☐ Mammogram ☐ Clinical breast exam

Test date: ____/____/____ Results: ____

B. Diagnosis

Diagnostic Procedures: _____

Final Diagnosis: _____

Stage at diagnosis: _____ (AJCC Classification, 1988)

Date: ____/____/____

Status of Final Diagnosis: _____

Date: ____/____/____

Status of Treatment: _____

Date: ____/____/____

Notes: _____

C. Attempts To Contact

Date: ____/____/____

Method: _____

Reason for Contact: _____

Date: ____/____/____

Method: _____

Reason for Contact: _____

Date: ____/____/____

Method: _____

Reason for Contact: _____

Notes: _____

PART III. NEW MEXICO TUMOR REGISTRY DATA.

A. Diagnosis.

Summary Stage: _____ (NMTR Summary)

No cancer-directed surgery: _____

**B. Treatment History. First Course Of Breast Cancer Therapy.
(4 Months Unless Otherwise Indicated).**

1.) Type Of Cancer-Directed Surgery.

Primary 1:

Site Specific Surgery Type: _____

Date Treatment Initiated: ____/____/____

Chart Narrative: _____

Facility Code: _____

Primary 2:

Site Specific Surgery Type: _____

Date Treatment Initiated: ____/____/____

Chart Narrative: _____

Facility Code: _____

Additional Surgeries:

Site Specific Surgery Type: _____

Date Treatment Initiated: ____/____/____

Chart Narrative: _____

Facility Code: _____

Site Specific Surgery Type: _____

Date Treatment Initiated: ____/____/____

Chart Narrative: _____

Facility Code: _____

2.) *Chemotherapy.*

Type: _____ Agents Administered: _____
Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Indicate Appts. Missed:

____ / ____ / ____	Reason: _____
____ / ____ / ____	Reason: _____
____ / ____ / ____	Reason: _____

Chart Narrative: _____

Facility Code: _____

3.) *Radiation*

Type: _____ Radiation sequence with surgery: _____
Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Indicate Appts. Missed:

____ / ____ / ____	Reason: _____
____ / ____ / ____	Reason: _____
____ / ____ / ____	Reason: _____

Chart Narrative: _____

Facility Code: _____

4.) *Hormonal.*

Type: _____ Agents Administered: _____
Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Indicate Appts. Missed:

____ / ____ / ____	Reason: _____
____ / ____ / ____	Reason: _____
____ / ____ / ____	Reason: _____

Chart Narrative: _____

Facility Code: _____

5.) *Immuno Therapy / Biological Response Modifiers.*

Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: ____ ____ ____ ____

Indicate Appts. Missed:

____/____/____ Reason: _____
____/____/____ Reason: _____
____/____/____ Reason: _____

C. OTHER CANCER DIRECTED THERAPY. (Clinical Trials/Experimental)

Type: ____

Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: ____ ____ ____ ____

D. SUBSEQUENT TREATMENTS. Greater than or equal to 4 months.

Type: ____

Date Treatment Initiated: ____/____/____ Date Treatment Completed: ____/____/____

Chart Narrative: _____

Facility Code: ____ ____ ____ ____

E. PATIENT STATUS: ☐ Alive ☐ Dead

Last Date of Activity: ____/____/____

Date of Death: ____/____/____ Cause of Death: ____ ____ ____ ____

F. FOLLOW-UP STATUS.

F-Up Phys/Hosp Code: ____ ____ ____ ____
Surgeon: ____ ____ ____ ____

PART IV. ABTRACTOR INFORMATION

A. ABSTRACTED BY: _____ DATE THIS FORM COMPLETED: ____/____/____

Patient Diagnostic & Treatment Summary Report **CODESHEET (B&CC)**

PART I.

ETHNICITY

- 00 = NonHispanic White
- 01 = Hispanic
- 02 = African American
- 03 = Asian
- 04 = Amer American
- 05 = Other (specify: _____)
- 09 = Unknown

PART II. B.

DIAGNOSTICPROCEDURES

- 1 = Diagnostic mammogram views
- 2 = Repeat Breast Exam/Consultation
- 3 = Ultrasound
- 4 = Biopsy/Lumpectomy
- 5 = Fine Needle/Cyst aspiration
- 6 = Other procedure (specify: _____)
- 9 = Unknown

STAGE AT DIAGNOSIS

- 0 = cancer in situ
- 1 = Stage I*
- 2 = Stage II*
- 3 = Stage III*
- 4 = Stage IV*
- 5 = unknown
- 6 = breast cancer not diagnosed

FINAL DIAGNOSIS

- 1 = Cancer in situ
- 2 = Cancer, invasive
- 3 = No breast cancer diagnosed

STATUS OF FINAL DIAGNOSIS

- 1 = Work-up complete
- 2 = Work-up pending
- 3 = Lost to follow-up
- 4 = Diagnostic follow-up refused

STATUS OF TREATMENT

- 1 = Treatment initiated
- 2 = Treatment pending
- 3 = Lost to follow-up
- 4 = Treatment refused

PART II. C.

METHOD OF FOLLOW-UP CONTACT

- 1 = Letter
- 2 = Telephone
- 3 = Homevist
- 4 = Other (specify: _____)

PART III. A. SEER CODES

NO CANCER-DIRECTED SURGERY/UNKNOWN

- 00 = No surgical procedure
- 01 = Incisional, needle, or aspiration biopsy of other than primary site
- 02 = Incisional, needle, or aspiration biopsy of primary site
- 03 = Exploratory ONLY (no biopsy)
- 04 = Bypass surgery, -ostomy ONLY (no biopsy)
- 05 = Exploratory ONLY AND incisional, needle or aspiration biopsy of primary site or other sites
- 06 = Bypass surgery, -ostomy ONLY AND incisional, needle or aspiration biopsy of primary site or other sites
- 07 = Non-cancer directed surgery, NOS
- 09 = Unknown if surgery done

PART III. B. 1.

TYPE OF CANCER-DIRECTED SURGERY

- 10 = Partial/less than total mastectomy (includes segmental mastectomy, lumpectomy, quadrantectomy, tylectomy, wedge resection, nipple resection, excisional biopsy, or partial mastectomy, NOS) WITHOUT dissection of axillary lymph nodes
- 20 = Partial/less than total mastectomy WITH dissection of axillary lymph nodes
- 30 = Subcutaneous mastectomy WITH/WITHOUT dissection of axillary nodes
- 40 = Total (simple) mastectomy (breast only) WITHOUT dissection of axillary lymph nodes
- 50 = Modified radical/total (simple mastectomy (may include portion of pectoralis major) WITH dissection of axillary lymph nodes
- 60 = Radical mastectomy WITH dissection of majority of pectoralis major WITH dissection of axillary lymph nodes
- 70 = Extended radical mastectomy (code 60 PLUS internal mammary node dissection; may include chest wall and ribs)
- 80 = Surgery of regional and/or distant site(s)/node(s) ONLY
- 90 = Mastectomy, NOS; Surgery, NOS

PART III. B. 2.

CHEMOTHERAPY

- 0 = None
- 1 = Chemotherapy, NOS
- 2 = Chemotherapy, single agent
- 3 = Chemotherapy, multiple agents (combination regimen)
- 7 = Patient or patient's guardian refused chemotherapy
- 8 = Chemotherapy recommended, unknown if administered
- 9 = Unknown

PART III. B. 3.

RADIATION

- 0 = None
- 1 = Beam radiation
- 2 = Radioactive implants
- 3 = Radioisotopes
- 4 = Combination of 1 with 2 or 3
- 5 = Radiation, NOS - method or source not specified
- 7 = Patient or patient's guardian refused radiation therapy
- 8 = Radiation recommended, unknown if administered
- 9 = Unknown

RADIATION SEQUENCE WITH SURGERY

- 0 = No radiation and/or cancer-directed surgery
- 2 = Radiation before surgery
- 3 = Radiation after surgery
- 4 = Radiation both before and after surgery
- 5 = Intraoperative radiation
- 6 = Intraoperative radiation with other radiation given before or after surgery

9 = Sequence unknown, but both surgery and radiation were given

PART III. B. 4.

ENDOCRINE (HORMONE/STEROID) THERAPY

0 = None

1 = Hormones (including NOS and antihormones)

2 = Endocrine surgery and/or endocrine radiation (if cancer is of another site)

3 = Combination of 1 and 2

7 = Patient or patient's guardian refused hormonal therapy

8 = Hormonal therapy recommended, unknown if administered

9 = Unknown

PART III. B. 5.

BIOLOGICAL RESPONSE MODIFIERS

0 = None

1 = Biological response modifiers

7 = Patient or patient's guardian refused biological response modifiers

8 = Biological response modifiers recommended, unknown if administered

9 = Unknown

PART III. C.

OTHER CANCER-DIRECTED THERAPY

0 = No other cancer-directed therapy except as coded elsewhere

1 = Other cancer-directed therapy

2 = Other experimental cancer-directed therapy (not included elsewhere)

3 = Double-blind clinical trial, code not yet broken

6 = Unproven therapy (including laetrile, krebiozen, etc.)

7 = Patient or patient's guardian refused therapy which would have been coded 1-3 above

8 = Other cancer-directed therapy recommended, unknown if administered

9 = Unknown

APPENDIX D

**LIST OF EXISTING QUESTIONNAIRES
IN BREAST CANCER**

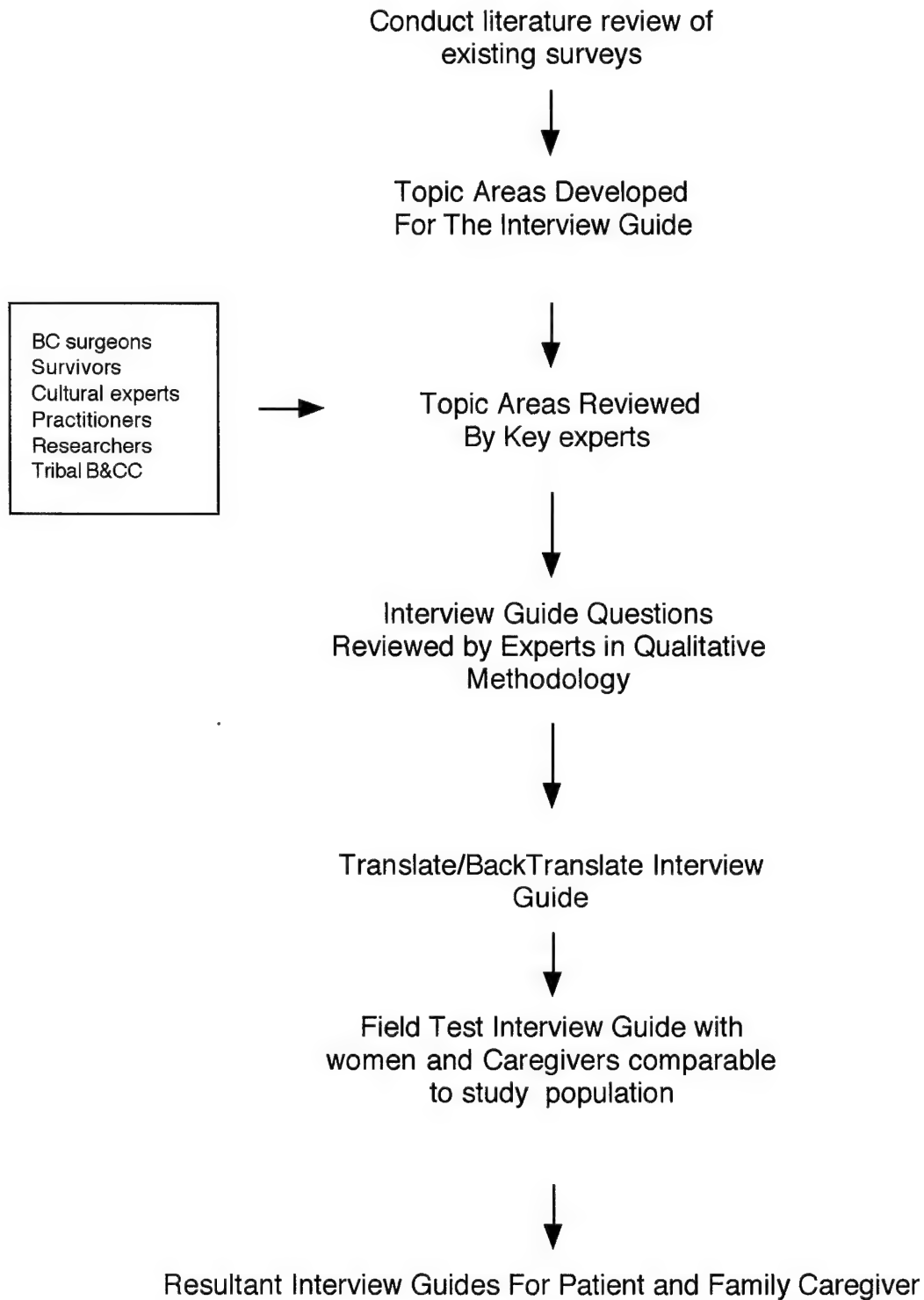
- Saint-Germain, Michelle A., Longman, Alice J. / Breast Cancer Prevention for Older Hispanic Women.
- Dodds, Max E., Dowd, Sharon L., Choi, Kelly. / Breast Cancer Screening Program Pre-Test. PS.
- Rimer, Barbara K., Davis, Sharon W., Engstrom, Paul F., / Breast Cancer Interview. PS.
- Dodds, Max E., Dowd, Sharon L., Choi, Kelly. / Breast Cancer Screening Program Post-Test. PS.
- Keane, Sarah McDermott. / Breast Cancer Needs Assessment.
- Dodds, Max E., Dowd, Sharon L., Choi, Kelly. / Breast Cancer Screening Program Satisfaction
- Ward, Sandra E., Griffin, Joan. / Breast Cancer Information Test-Revised.
- Nettles-Carlson, Barbara. / Breast Self-Examination Knowledge, Attitudes, and
- Wiecha, John M. / Breast Cancer Screening Confidence Survey of Physicians.
- McFall, Stephanie L., Warnecke, Richard B., Kaluzny, / "breast cancer treatment" interview. PS.
- Rimer, Barbara K., Davis, Sharon W., Engstrom, Paul F., / Combined Interview. PS.
- Bennicke, Kim, Conrad, Carsten, Sabroe, Svend, / "smoking habits...and breast cancer" interview. PS.
- Owens, Richard Glynn, Daly, Joanne. / Breast Screening Questionnaire. PS.
- Rutledge, Dana Nelson. / Modified Champion Health Belief Model Scale.
- Saint-Germain, Michelle A., Longman, Alice J. / "breast cancer" survey. PS.
- Hyman, Ruth Bernstein, Baker, Stephen. / Hyman-Baker Mammography Questionnaire. PS.
- Saint-Germain, Michelle A., Longman, Alice J. (Spanish / "breast cancer" survey-"Spanish". PS.
- Cawley, Margaret M., Kostic, Jacqueline, Cappello, / Assessment of Information-Psychosocial Needs of Women
- Burg, Mary Ann, Lane, Dorothy S., Polednak, Anthony P. / "breast cancer screening tests". PS.
- Boyd, N.F., Selby, P.J., Sutherland, H.J., Hogg, S. / "clinical status of patients with breast cancer...linear
- Aiken, Leona S., West, Stephen G., Woodward, Claudia / "mammography.... pretest" questionnaire. PS.
- Glenn, Betty, L., Moore, Linda A. / Breast Self-Examination Practices, Beliefs and Background
- Ward, Sandra, Griffin, Joan. / Breast Cancer Information Test-Revised.
- Steinberg, Maurice D., Julian, Mary Ann, Wise, Leslie. / "breast cancer surgery"-"husbands' questionnaire". PS.
- Steinberg, Maurice D., Julian, Mary Ann, Wise, Leslie. / "breast cancer surgery"-"patients"-"questionnaire".
- Salazar, Mary K., Wilkinson, W. E., DeRoos, R. L., / "breast cancer survey"-"interview" with "categories".
- King, Eunice, Rimer, Barbara K., Balsheim, Andrew, / "mammography-related beliefs". PS.
- Champion, Victoria L. / Health Belief Model Scale. PS.
- Rothman, Alexander, J., Salovey, Peter, Turvey, / Attitudes About Breast Cancer and Mammography
- Lauver, Diane. / "care-seeking patterns...breast cancer". PS.
- Rakowski, William, Fulton, John P., Feldman, Judith P. / "stages-of-mammography adoption" survey. PS.
- Price, James H., Desmond, Sharon M., Slenker, Suzanne, / "perceptions of breast cancer and mammography". PS.
- Longman, Alice J., Saint-Germain, Michelle A., Modiano, / "access to and rise of breast cancer screening services".
- Longman, Alice J., Saint-Germain, Michelle A., Modiano, / "access to and rise of breast cancer screening services".
- Lipnick, Robert J., Buring, Julie E., Hennekens, / "oral contraceptives and breast cancer". PS.
- Champion, Victoria L. / Health Belief Model scales-"revised". PS.
- Champion, Victoria L. / Health Belief Model Constructs. PS.
- Aiken, Leona S., West, Stephen G., Woodward, Claudia / "mammography.... posttest" questionnaire. PS.
- Taylor, S. E., Lichtman, R. R., Wood, J. V. / "beliefs about control". SS.
- Swinker, Marian, Arbogast, James G., Murray, Sharon. / "breast cancer and mammography behavior, knowledge, and
- Stillman, M. / Health Beliefs Instrument. CS.
- Rothman, Alexander, J., Salovey, Peter, Turvey, / "knowledge about breast cancer and mammography". PS.
- Rippetoe, Patricia A., Rogers, Ronald W. / "beliefs...breast cancer...breast self-examination". PS.
- Rippetoe, Patricia A., Rogers, Ronald W. / "styles of coping with the threat of breast cancer". PS.
- Northouse, Laurel L. / Social Support Questionnaire.
- Mock, Victoria. / Body Image Visual Analogue Scale.
- Helgeson, Vicki S. / "personal and vicarious control...interview"-"adapted".
- Holmberg, Lars, Ohlander, Eva M., Byers, Tim, Zack, / "food frequency questionnaire". PS.
- Jones, H. / Breast Cancer Questionnaire. SS.
- Johnson, J. / Pain Intensity-Distress Scales-"modified". PS.
- Johnson, Sarah C., Spilka, Bernard. / "patient-clergy contacts, actions, and evaluations". PS.
- Brailey, L. Joan. / Breast Self-Examination Questionnaire. PS.
- Bradburn, Norman M. / Affect Balance Scale.
- Carver, Charles S., Scheier, Michael F., Weintraub, J. / COPE. SS.
- Cassileth, B. R., Lusk, E. J., Bodenheimer, B. J., / "expectations about...development of...side effects of
- Lazarus, R. S., Folkman, S. / Ways of Coping Questionnaire.
- Lewis, Frances Marcus, Hammond, Mary A., Woods, Nancy / "socioeconomic status". PS.
- Lezak, M. D. / Alphabet Backward. SS.
- Cawley, Margaret, Kostic, Jacqueline, Cappello, Carol. / "physical and psychosocial aspects"-"lumpectomy". PS.
- Dodd, Marilyn J. / Chemotherapy Knowledge Questionnaire. PS.
- Derogatis, Leonard R. / Brief Symptom Inventory.
- Manne, Sharon L., Sabbioni, Marzio, Bovbjerg, Dana H., / Physical Symptoms Questionnaire.
- Massey, Veta. / Health Belief Questionnaire. PS.
- McCorkle, R., Young, K. / Symptom Distress Scale.
- McCorkle, R. / Symptom Distress Scale-"modified". SS.
- McCubbin, H. I., Larsen, A. S., Olson, D. H. / Family Coping Strategies Scale.

Berscheid, E., Walster, E., Bohrnstedt, G. / Body Image Scale.
 Mesulam, M. / The Digit Span. SS.
 Meyerowitz, Beth E. / Physical Discomfort Inventory. PS.
 Mishel, M. / Mishel Uncertainty in Illness Scale.
 Mishel, M. / Parent Perception of Uncertainty Scale. .
 Hankin, Jean H., Nomura, Abraham MY, Lee, James, / "diet history questionnaire". PS.
 Nerenz, D. R., Leventhal, H., Love, R. / Side Effects Checklist.
 Beck, Aaron T. / Beck Hopelessness Scale.
 Norbeck, J., Lindsey, A., Carrieri, V. / Norbeck Social Support Scale. SS.
 Northouse, L.L. / Fear of Recurrence Scale. SS.
 Northouse, Laurel L. / Social Support Questionnaire.
 Haberman, M. R., Woods, N. F., Packard, N. J. / Demands of Illness Inventory. SS.
 Olson, D. H., McCubbin, H. I., Barnes, H., et al. / Family Adaptability and Cohesion Evaluation Scale II.
 Arathuzik, Diane. / "coping responses used by patients to deal with pain".
 Derogatis, L. R. / Psychosocial Adjustment to Illness Scale.
 Radloff, L. S. / Center for Epidemiologic Studies Depression Scale.
 Radloff, Lenore, S. / Center for Epidemiological Studies Depression Scale.
 Cimprich, B. / Attentional Function Index.
 Rimer, Barbara K., Davis, Sharon W., Engstrom, Paul F., / US HEALTHCHECK Assessment Form. PS.
 Arathuzik, Diane. / "the pain experience"—"questionnaire". PS.
 Arathuzik, Diane. / Pain Intensity-Distress Scales—"modified". PS.
 Guagnoli, E., Mor, V. / Profile of Mood States—"brief version". SS.
 Guagnoli, Edward, Cleary, Paul D. / "comorbid disease severity score". PS.
 Ronis, D.L. / "intent scale". SS.
 Ronis, D.L. / "social influence". SS.
 Ronis, D.L. / "confidence...performing BSE". SS.
 Champion, Victoria L. / Health Belief Model Scales—"revised". PS.
 Greer, S. / Mental Adjustment to Cancer.
 Rotter, Julian B. / Rotter Internal External Locus of Control Scale. SS.
 Arathuzik, Diane. / "pain-coping responses". PS.
 Arathuzik, Diane. / "pain experience". PS.
 Andrykowski, M. A., Redd, William H., Hatfield, A. K. / "anxiety...visual analog scale". SS.
 Alexander, Mary A. / Evaluation of Objectives.
 Cella, David F., Tulsky, David S., Silberman, Margaret, / Functional Assessment of Cancer Therapy—Form B. PS.
 Sarason, I. G., Levine, H. M., Basham, R. B., Sarason, / Social Support Questionnaire.
 Satariano, William A., Ragheb, Nawal E., Buck, Karen / "level of functioning"—"Instrumental Activities of Daily
 Schain, Wendy S., Wellisch, David K., Pasnau, Robert / Psychosocial Reactions to Different Types of Breast
 Scheier, M. F., Carver, C. S. / Life Orientation Test.
 Scheier, Michael F., Carver, Charles S. / Life Orientation Test.
 Selby, P. J., Chapman, J. A. W., Etzadi-Amoli, J., / "quality of life of cancer patients"—"linear analogue
 Spanier, G. B. / Dyadic Adjustment Scale.
 Stanton, Annette L., Snider, Pamela R. / "cognitive appraisal". PS.
 Cella, David F., Tulsky, David S., Silberman, Margaret, / Functional Assessment of Cancer Therapy—Form G. PS.
 Cella, David F., Tulsky, David S., Silberman, Margaret, / Functional Assessment of Cancer Therapy—Form L. PS.
 Ellison, E. H. / Family Peer Relationship Questionnaire. SS.
 Strauss, Lynn M., Solomon, Laura J., Costanza, Michael / "breast self-examination"—"questionnaire". PS.
 Friedman, Lois C., Baer, Paul E., Lewy, A., Lane, / Cancer Adjustment Survey.
 Folkman, S., Lazarus, R. / Ways of Coping Questionnaire—"revised". SS.
 Timko, Christine. / "intentions to delay or not delay seeking medical care".
 Cella, David F., Tulsky, David S., Silberman, Margaret, / Functional Assessment of Cancer Therapy—Form C. PS.
 Aitken, R. C. B. / Visual Analog Mood Scale.
 Ward, Sandra E., Vieregut, Gail, Tormey, Douglas, / Problems Checklist.
 Ward, Sandra E., Vieregut, Gail, Tormey, Douglas, / "perceived timeline". PS.
 Ward, Sandra E., Vieregut, Gail, Tormey, Douglas, / "efficacy of treatment". PS.
 Cella, David F., Tulsky, David S., Silberman, Margaret, / Functional Assessment of Cancer Therapy—Form H & N.
 Willett, W. C., Stampfer, M. J., Colditz, G. A., / Nurses Health Study Questionnaire. SS.
 Willett, W. C., Sampson, L., Stampfer, M. J., Browne, / Food-Frequency Questionnaire. SS.

APPENDIX E

**SEQUENTIAL DEVELOPMENT OF THE
INTERVIEW GUIDE**

SEQUENTIAL DEVELOPMENT OF THE INTERVIEW GUIDE



APPENDIX F

**PROJECT DIFFUSION IN THE
SCIENTIFIC COMMUNITY**

BARRIERS TO BREAST CANCER HEALTH CARE



*Review of Literature and
Recommendations for New Mexico*

Delays and Refusals in Treatment for Breast Cancer Among American Indian and Hispanic Women

Under the direction of Elba L. Saavedra, MS, this study will increase the understanding of patient perceptions in the management of breast cancer among American Indian and Hispanic patients. The cultural beliefs, language, and attitudinal variables associated with breast cancer management will be explored. The study results are expected to provide baseline data for developing intervention strategies for improving breast cancer outcomes in these populations. Findings will be submitted for publication, and presented to the Hispanic and American Indian communities and to clinicians.

Factors Important in the Development of Breast Cancer

Under the direction of Dr. Sylvia Ramos, this study will elucidate the factors which may contribute to the development of breast cancer in the various ethnic groups in New Mexico, particularly Hispanic women. Patients will complete a clinical questionnaire and are provided long-term follow-up. The questionnaire asks about various factors which may allow development of a risk profile.

Basic Research and Clinical Trials

New Mexico is fortunate to have a number of excellent clinical facilities for the treatment of breast cancer, many of which conduct active research programs. Albuquerque is home to the majority of these facilities, including the University of New Mexico Health Sciences Center which includes the New Mexico Cancer Research and Treatment Center and the New Mexico Tumor Registry. Also located in Albuquerque are New Mexico Oncology-Hematology Consultants, Presbyterian Healthcare Services, the Center for Managed Care Research (Lovelace Institutes), St. Joseph's Cancer Center, and Surgical Associates P.A.. Other New Mexico facilities include the Indian Health Service, San Juan Regional Cancer Center and Santa Fe Hematology-Oncology P.A..

DIRECTORY OF BREAST CANCER RESEARCH



IN NEW MEXICO

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Health Sciences Center
School of Medicine
Research Center for Ethnic Populations (RCEP)
BMSB Box 709
Albuquerque, NM 87131-5141
Telephone: (505) 272-2355
Fax: (505) 272-2400
E-mail: elsaave@unm.edu

Title of Research Study: Delays and Refusals in Treatment for Breast Cancer Among Native American and Hispanic Women with Breast Cancer

Principal Investigator: Elba L. Saavedra, M.S.

Doctoral student - College of Education/Health Education

Dates of project period: From 09-01-96 through 08-31-99

Abstract: The aims of this study are to increase the understanding of patient perception in the management of breast cancer among Native American and Hispanic patients. The cultural beliefs, language, and attitudinal variables associated with breast cancer management will be explored. The study results are expected to provide baseline data for developing intervention strategies for improving breast cancer outcomes in these populations. Findings will be submitted for publication and presented to the Hispanic and Native American communities and to clinicians.

Roswell Record

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Women's health conference set

79
The University of New Mexico Health Sciences Center is co-sponsoring a regional conference on women's health at the Hilton Hotel in Santa Fe Monday through Wednesday. The conference, "Beyond Hunt Valley: Research on Women's Health for the 21st Century," is sponsored by the Office of Research on Women's Health, National Institutes of Health.

"Research that will impact the health of women deserves focus and funding," said Dr. Jane E. Henney, vice president of Health Sciences at the university. "It is an honor for us to be asked to help set the nation's research agenda at this conference. Taking time to carefully chart our research course will benefit women for generations to come."

The conference will assess, update and advance the national agenda for women's health research for the coming decade. Workshops will focus on the differences among populations of women and factors that contribute to the differences in health status and health outcomes.

The conference in Santa Fe is the last of three regional conferences. Recommendations from the regional meetings will result in a final report which will identify priorities for research on women's health in the 21st century.

In 1991, as a result of a growing awareness that women's health issues were often not appropriately addressed, a meeting was held in Hunt Valley, Md., to assess the state of and develop an agenda for women's health research. The report from that meeting served as the broad blueprint and resulted in the development of the Office of Women's Health Research.

Dr. Gloria Sarto, professor of obstetrics and gynecology at the university's Health Sciences Center, was instrumental in the development of the office and is currently on its

advisory committee. She is also the president of the Society for the Advancement of Women's Health Research and will speak at the conference.

"This workshop has the tremendous potential to provide valuable guidance to the National Institutes of Health through the Office of Research on Women's Health and to the scientific community," said Sarto. "The goal of this regional workshop is to identify factors that contribute to differences in health status and health outcomes of women and to ensure that a biomedical research agenda addresses such factors."

Women's health research receives high priority at the Health Sciences Center. One of Sarto's projects involves maternal/fetal blood research. Dr. Carla Herman, assistant professor in the Department of Medicine, has a grant from the office to study ethnic variations in women's understanding of hysterectomy and the use of hormone replacement therapy and menopause.

Herman also is funded by the New Mexico Department of Health to study strategies for educating primary care physicians in cervical cancer screening.

She is also gathering data on the existence of barriers to mammography screening for rural and urban women in New Mexico.

Elba Saavedra, a research scientist at the university's Center for Population Health, has a U.S. Army fellowship to study why Native American and Hispanic women delay or refuse treatment for breast cancer more frequently than women in other populations. She is also working on a New Mexico Department of Health grant about the timeliness in breast cancer care.

To register for the conference, call (301) 495-0986.

APPENDIX G

**INVESTIGATOR PROFESSIONAL
DEVELOPMENT**

Professional Development

The following summary profiles the investigator's continued professional and academic activities since the submission of the original proposal. Research, academic coursework and mentoring, and participation in workshops and conferences, have combined to enhance her professional knowledge and skills as a future breast cancer investigator.

Review of the Literature on Breast Cancer Health Care

Extensive Literature Review on Barriers to Breast Cancer Care

The investigator's research over the last two years has included conducting a thorough review of the literature on barriers to breast cancer care. She served as lead author in the publication of *Barriers to Breast Cancer Care: A Review of Literature and Recommendations for New Mexico*. This review outlines the barriers to care that have been researched and documented in the literature on breast cancer health care. It identifies patient related barriers, provider related barriers, and health care system related barriers, which can be correlated with health outcomes. High-risk populations for developing breast cancer (older women and non-Hispanic white women), populations with increased mortality from breast cancer (African-American, Hispanic, and American Indian women) and populations with known barriers to care (low-income and rural women, certain racial and ethnic groups) are identified. The review offers a conceptual framework, categorization, and summarization of the findings, with applied relevance to breast cancer care in New Mexico.

Collaborations with Other Investigators

Regional Co-Principal Investigator on a Multi-Site Investigation Among Hispanic Breast Cancer Patients - *"Unidos Por La Salud, Assessment of Post-Treatment Knowledge and Attitudes Among Hispanic Women After Breast Cancer Therapy, A Multi-Site Cancer Initiative"*

Working in collaboration with regional Principal Investigator Dr. Christopher Urbina, at the University of New Mexico, the investigator functions as project director of this pilot study collecting data on Hispanic women with breast cancer. The aims of the study are the following: 1) to describe the women's experience of treatment and its impact on quality of life; 2) to assess the degree to which adverse reactions to treatment are a deterrent to completion of breast cancer treatment regimens; 3) to describe barriers to continuing care that are specific to Hispanic women.

Collaborations with Community and State Health Care Agencies

New Mexico Department of Health - Breast and Cervical Cancer Program

As a result of her master's thesis research, the investigator has developed close collaborative efforts with the New Mexico Breast and Cervical Cancer Control Program. Through these professional contacts, the investigator is exposed to current trends in breast cancer screening and diagnostic services for medically underserved women in New Mexico.

B&CC Program - Cancer Prevention and Control Advisory Council (CPCAC)

The investigator also serves as member of CPCAC, the advisory council to the Breast and Cervical Cancer Program. The council is made up of a broad spectrum of representatives of organizations, institutions, and providers in the state of New Mexico. By the broad nature of its membership, the council also serves to disseminate information to outlying areas and coordinate breast and cervical cancer control efforts statewide. This activity provides the

investigator with an understanding of current cancer control efforts around the state.

Indian Health Service (IHS) Cancer Prevention and Control Program

This program manages cancer control activities for American Indians and Alaska Natives nationwide. The Cancer Prevention and Control Program includes epidemiologists, support staff, and programmatic experts with substantial experience in cancer control among Native Americans. Through collaboration with this program, the investigator is provided with up to date information on tribal regulations and the institutional review board (IRB) process.

People Living Through Cancer - Cultural Outreach Committee

PLTC was founded by and for those coping with a cancer diagnosis, or the cancer of a friend or loved one. PLTC services includes outreach to Hispanic, American Indian, and African-American breast cancer survivors in New Mexico. The investigator has been working closely with PLTC and is now an active member of its cultural outreach committee, designed to increase awareness and education among ethnically diverse communities. The investigator will serve as facilitator for a workshop discussion on survivorship among diverse communities at the PLTC's annual state-wide survivorship conference on October 25th, 1997 (Appendix G).

A Gathering of Cancer Support

The Gathering of Cancer Support, directed by Mary P. Lovato, provides services such as one-to-one support, peer support, transportation to screening clinics and appointments, patient advocacy, and Keres-English translation. The investigator has been working with Ms. Lovato to facilitate implementation of the study with breast cancer patients from the Pueblos.

New Mexico Tumor Registry - Epidemiology and Cancer Control Program

The investigator has worked very closely with the NMTR since the completion of her master's thesis in 1995. The investigator has increased her knowledge of both the capabilities and limitations of the NMTR cancer registry database. NMTR director Dr. Charles Key and Program Manager Anna Marie Davidson have provided consultation and expertise on the development of the medical abstract form and IRB submission at the UNM Health Sciences Center. As a result of this work, the investigator has been trained by the NMTR staff on the use of the registry's database. This cancer database includes data on the patient (age, gender, race/ethnicity, county of residence, census tract, and zip-code), the cancer (site, histologic type, histologic grade, extent of disease), treatment (surgery, radiation, chemotherapy), and outcome (vital status at intervals after diagnosis, length of survival, cause of death). Dr. Key has expressed his appreciation of the improvement of the quality of the breast cancer database which results from the investigator's cross checking of the NMTR and B&CC Program records.

In summary, the investigator's professional activities since the submission of the original proposal have focused on developing and strengthening partnerships with community and state health agencies, consumer groups and the tribal governments. These activities contribute directly to the success and quality of the current study

Complimentary Academic Activities

Doctoral Degree Coursework

The following is a description of coursework for the current semester which compliments the investigator's research focus and the current study.

Qualitative Methodology: This doctoral level course is designed to develop understanding of the processes involved in qualitative research. Specifically, the course will devote attention to: 1) defining the research problem/site; 2) data collection methods - interviewing, observing, and inspecting documents; 3) data analysis; 4) maximizing the validity of the findings; and 5) enhancing the student's writing abilities.

Research Methods - SPSS: This course surveys topics in social science research methods with special emphasis on experimental and quasi-experimental design, data management, SPSS programming procedures, and statistical analysis.

Qualitative Data Analysis with QSR NUD•IST™ (Nonnumerical Unstructured Data Indexing, Searching and Theorizing): This workshop provides a basic overview of principles of qualitative data collection and analysis with real data from a class-generated mini-research projects as well as "hands-on" training in the use of QSR NUD•IST™.

Mentoring by University of New Mexico Faculty

Identified Study Mentors

Eli Duryea Ph.D. and Magdalena Avila Ph.D.- College of Education, Health Education Department.

The investigator has convened meetings with sponsoring faculty to:

1) identify project and research skill learning objectives, 2) review study design and instrument development, 3) discuss the process of interview guide development, 4) discuss new developments with Navajo Nation B&CC Program and Navajo IRB reorganization. The mentors continue to be available and involved with the investigator's study as planned.

Other Faculty

Carla Herman, MD, MPH - Assistant Professor of Medicine, Department of Internal Medicine.

Dr. C. Herman is a faculty member of the University of New Mexico School of Medicine, a researcher involved in women's health issues, and a member of the CPCAC advisory council of the B&CC Program. Dr. Herman's research interests include ethnic variability in health, breast cancer screening, and patient-provider communication. Dr. Herman has been available to the investigator for consultation on research related matters such as reviewing study protocols, methods, exchanging literature in breast cancer, and professional networking. Dr. Herman is also a member of the investigator's doctoral dissertation committee.

Professional Conferences and Presentations

November 1, 1996

Workshop Presentation: Barriers to Abnormal Mammography Follow-up for Hispanic Women at Breast and Cervical Cancer New Challenges, Third Annual Breast and Cervical Cancer Detection & Control Program Provider Conference. Albuquerque Convention Center, Albuquerque, New Mexico

November 17-21, 1996

Poster Presentation: No nos olvide: Research in the Hispanic community from design through implications. Baezconde-Garbanati, L., Muth, B. J., Nazario, C. M., Saavedra, E. L. at the American Public Health Association's 124th Annual Meeting and Exposition: Empowering the Disadvantaged: Social Justice in Public Health. Ms. Saavedra contributed the section on designing and conducting a multi-site interviewer training of bilingual and bicultural interviewers. for interviewing Hispanic women with abnormal mammograms and breast cancer.

December 6-8, 1996

Workshop Attendance: Cross-Cultural Research , Eleventh Annual Primary Care Research Methods and Statistics. San Antonio, Texas.

Participant: These workshops were conducted in a lecture style covering cross-cultural research methodology and qualitative and quantitative methods. Lecturing and addressing concerns were Susan Weller and Lee Pachter both well known qualitative researchers in medical anthropology. The investigator had a chance to discuss the current study and exchange ideas with these well known researchers in the field of cross-cultural research.

April 23-27, 1997

Conference Attendance: Cancer, Minorities & the Medically Underserved, 6th Biennial Symposium on Minorities, the Medically Underserved &

Cancer. Washington, DC. Attended workshops and networked with presenters with similar areas of research interests.

July 21, 1997

Workshop Participant: Beyond Hunt Valley: Research on Women's Health for the 21st Century, A Public Hearing and Scientific Workshop. Office of Research on Women's Health (ORWH) National Health Institutes. Santa Fe, New Mexico. Postmenopausal Years Working Group. Participated in discussion and recommendations from this group for a research agenda on women's health.

Scheduled Conference Attendance and Presentations

October 25, 1997

Workshop Presenter: Taking Strength From Our Cultures, a facilitated group discussion led by Ms. Saavedra with cancer survivors from diverse communities at People Living Through Cancer's annual state-wide survivorship conference: Moving Ahead - Living Without a Rear View Mirror. Albuquerque, New Mexico.

October 31-November 4, 1997

Conference Attendance: Era of Hope, Department of Defense Breast Cancer Research Program Meeting. Washington, DC. As a FY 1995 recipient, the investigator will take part in the meeting's goals and objectives.

January 8-10, 1998

Potential Workshop Presenter: Analysis of Timeliness from Abnormal finding to diagnosis among women diagnosed with breast cancer from 1991 to 1994 at Progress and Survival: Native Women and Cancer, The University of Arizona Health Sciences Center. Tucson, Arizona.

Publications

Published

1. Saavedra, E. L., Urbina, C. E. (May, 1996). Directory of Breast Cancer Research. New Mexico Department of Health.
2. Saavedra, E. L., Archibeque, M. (August, 1997). Barriers To Breast Cancer Health Care: Review Of Literature And Recommendations For New Mexico. New Mexico Department of Health.

In Progress

Baezconde-Garbanati, L., Muth, B. J., Nazario, C. M., Saavedra, E. L.. No Nos Olvide: Research In The Hispanic Community From Design Through Implications. To be submitted to peer review journals.

People Living Through Cancer

Join Us!

There are more than 30,000 cancer survivors living in New Mexico. We are a reflection of this region's diverse population — men, women, Hispanics, Anglos, American Indians, African Americans and Asian Americans. We come from all walks of life, but have a common life-changing experience — a cancer diagnosis.

Our annual survivorship conference brings us together to learn, to share, and to gain strength from each other.

About People Living Through Cancer . . .

People Living Through Cancer, Inc., was founded in 1983 by and for those dealing with a cancer diagnosis or the cancer of a friend or loved one. People Living Through Cancer's programs help members make informed choices and improve their quality of living by sharing in a community of people who have "been there."

People Living Through Cancer sponsors a wide variety of support and education services to thousands of New Mexicans every year. The organization does not endorse any particular treatment or avenue to address illness. We recognize that individuals are different, and we support their choices.

presents its

Annual State-wide Survivorship Conference



October 25, 1997
Monte Vista Christian Church
3501 Campus Blvd. NE
Albuquerque, New Mexico

8:30 a.m. - 4:30 p.m.
(registration 7:30 - 8:30 a.m.)

Keynote Speaker



"Living Without a Rear View Mirror"

Amy Harwell, MA, is a cancer survivor and founder of Joshua's Tent. Ms. Harwell is the author of two books, *Ready to Live, Prepared to Die: A Provocative Guide to the Rest of your Life* and *When Your Friend Has Cancer, How You Can Help*.

Morning Concurrent Workshops

A. Taking Strength From Our Cultures - Elba Saavedra, M.S.
Facilitated group discussion: 1) to acknowledge the strengths of various cultural groups in New Mexico and their histories of coping with illness and disease, and 2) to develop constructive approaches to survivorship in diverse ethnic communities.

B. The Emotional Side of Having Cancer: What To Do with All the Feelings - Laura Glick, L.I.S.W.
Navigate the waters of the many feelings that come along with cancer and assess whether your style of expression is working for you.

C. Heredity Issues and Cancer - Sally Bachofer, M.D.
Understand the inherited susceptibility to cancer and how to interpret the news on genetic tests.

D. What's Love Got To Do With It? - Susan K. Rush, M.A.
Explore the body-mind-spirit connection and the concept of self-blessing.

E. Poetry as a Tool to Express the Emotions that Accompany the Cancer Experience - Carol Jordan, M.S.W.
Hear from survivors through their poetry, discover how poetry can help normalize the feelings that come with a cancer diagnosis, and find creative outlets for those feelings.

F. Personal Retreat: A Tool for Balancing the Body, Mind, and Soul - Glenda Logan Harrison
Learn to structure periodic personal retreats to increase your awareness in the present moment and the joy that is possible from within.

G. Imagery for Relaxation — Keeping Your Cool When Your World is Too Hot - Jean Stouffer, C.Ht.
Use the mind to achieve and maintain a relaxed state and break the cycle of chronic stress.

H. Group Support Session - Don Giese and Betty Rein
Led by trained, experienced facilitators who are veterans of the cancer experience; an opportunity for sharing experiences and discussing concerns with others who have "been there."

Afternoon Concurrent Workshops

I. The Healing Art of Writing (participatory) - Julie Reichert, M.A.
Explore how writing can be used both as a means of expression and for deeper understanding of personal experience.

J. Alternative Health-care Treatments for Cancer - Curtis H. Jones, Ph.D.
Learn about the variety of alternative and complementary therapies that aim to strengthen the immune system and kill cancer cells.

K. Touching Base with Your Spiritual Center - Chaplain Fabian M. Gagnon
How religion can be a source of strength, hope, and energy during illness. Open to those of all faiths.

L. Ready to Live — Prepared to Die - Amy Harwell, M.A.
A survivor of recurrent cancer shares her story of facing death and addressing the tough medical, ethical, emotional, and spiritual issues.

M. Walking the Gate to Heaven: An Introduction to the Dromenon - Donn Nielsen, M.A., L.P.C.C.
An ancient European maze that takes you into your inner world.

N. Growing Up when Your Parent Has Cancer: Helping the Children in the Family - Teresa A. Dubuque, M.A., L.P.C.
Presentation and discussion on developmental issues, knowing what reactions are normal, dealing with fears and questions, how much to tell children.

O. The Paradox of Healing - Jamie McDonald, M.S.W., L.I.S.W., Kathryn Edgar, M.A., and Tina Carlson, R.N.
A panel discussion on spiritual healing and an exploration of cardiologist Herbert Benson's work on healing in medicine.

Closing Session



"Where the Past Meets the Future"

Stephen P. Barrilleaux, Ph.D., is a psychologist with more than 15 years' experience working with people who have life-threatening illness.

Closing Ceremony

Sam English will lead us in a Native American blessing to close this year's conference. Mr. English is a member of the Chippewa tribe in North Dakota and a noted Albuquerque artist.